Occupationnal Health

Mandatory notification of Mesotheliomas

Results of the pilot phase and recommendations for a national implementation

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The annual number of new mesothelioma cases in France is estimated at between 800 and 1,200, i.e. accounting for 0.3% of all cancers. Mesotheliomas mainly affect men (two-thirds of cases). They are located in the serous membranes, mainly in the pleura, sometimes in the peritoneum and, rarely, in the pericardium or the tunica vaginalis testis.

Asbestos is currently the only proven risk factor of mesothelioma. Exposure to asbestos, which might have occured several decades before diagnosis, is mostly occupational. It can also be environmental (natural, anthropic, domestic, passive intra-mural or para-occupational origin).

The French National Mesothelioma Surveillance Program (PNSM – Programme national de surveillance des mésothéliome) was set up in 1998 to monitor pleural mesotheliomas. This program currently covers 23 "départements" in 12 regions, i.e. almost 30% of the French metropolitan population. According to the data collected in PNSM, between 77 and 90% of the pleural mesotheliomas diagnosed in men have been attributed to occupational exposure to asbestos. This proportion is only 27 to 50% in women, which suggests that the role of environmental exposure to asbestos could be underestimated.

The French public authorities decided to introduce a policy for the mandatory notification of mesotheliomas (MN) to complete the knowledges provided by PNSM. It was a request of the Ministry of Health (General Health Directorate). It is part of the 2009-2013 Cancer Plan (measure 9.1). The procedure to declare a reportable disease is defined by the Public Health Code. MN does not replace the notifiable occupational disease system.

1. MN of mesotheliomas: complementary objectives to the PNSM

The MN of mesotheliomas must be set up in two steps: a pilot phase [1] followed by a national implementation as soon as regulatory texts are published.

Reiterating the terms of the decision published by the High Council for Public Health (Haut conseil de santé publique - HCSP) in October 2010, the MN of mesotheliomas, set up to further epidemiological knowledges, will supplement the PNSM to achieve two objectives:

- strengthen the epidemiological monitoring of mesotheliomas in all anatomical sites (pleura, peritoneum and other sites) throughout France (metropolitan and overseas territories),
- identify cases without occupational exposure to asbestos. These cases will then be studied in an exposure survey aimed at increasing awareness of environmental causes. Three populations will be specifically targeted: women, the under 50 year-olds and non pleural mesotheliomas.

These objectives complement those of the PNSM, expert system for diagnosis (anatomo-pathological and clinical), occupational exposure and medical-social aspects for pleural mesotheliomas. The existence and relevance of the PNSM are not affected by the MN.

2. The pilot phase in the MN of mesotheliomas

The pilot MN phase was carried out over a period of 6 months, from 1 January to 30 June 2011. Once approved by the HCSP, this pilot phase also received a favourable opinion from the "Comité consultatif sur le traitement de l'information en matière de recherche dans le domaine de la santé" (CCTIRS) in November 2010, followed by authorisation from the "Commission nationale de l'informatique et des libertés" (Cnil) in December 2010. It was carried out in six pilot regions: three regions covered by the PNSM (Aquitaine, Ile-de-France, Provence-Alpes-Côte d'Azur) and three regions not covered by the PNSM (Auvergne, Lorraine, Midi-Pyrénées).

This phase aimed to test the reporting of new cases of mesotheliomas and the ability of the system to respond to the two objectives in order to propose more appropriate strategies for implementing the system nationwide.

SFP Société Française de Pathologie
FFP Fédération Française de Pneumologie
SPLF Société de Pneumologie de Langue Française
CPHG
RENAPE Centre National de Référence des Tumeurs Rares du Péritoine
Institut National du Cancer
Liberté • Égalité • Fraternité République Française
Ministère du Travail, de l'Emploi et de la Santé
InVS French Institute for Public Health Surveillance

An active information stage among potential reporting physicians: the relevance of networks and professional societies

Raising awareness of potentially reporting physicians (pathologists, chest physicians, surgeons and oncologists) was an important stage prior to the launch of the pilot phase and during its implementation. Pathologists who formally diagnose cancer play a key role in reporting cases. There are currently around 1,500 in France. Potentially reporting clinicians are mostly chest physicians (around 1,700), gastrointestinal surgeons (approximately 630), chest surgeons (around 240) and respiratory and gastrointestinal oncologists.

The project was highly supported by professional bodies in order to reach all of these physicians [pathologists: "Société française de pathologie" (SFP); chest physicians: "Société de pneumologie de langue française" (SPLF), "Fédération française de pneumologie" (FFP)]; "Conseil national de cancérologie" (CNC), Regional Oncology Networks ("Réseaux régionaux de cancérologie" - RRC) and PNSM teams working in conjunction with their reporting networks (pleura). The information has also been relayed by the "Conseil national de l'Ordre des médecins" (Cnom).

The awareness of gastrointestinal specialists has also been raised with the support of the "Réseau national des tumeurs rares du péritoine" (Renape). As of 1 July 2011, this network comprised 23 Regional hospitals (11 "CHU", 12 French Comprehensive Cancer Centers - FCCC) in 15 metropolitan regions. This network operates in close conjunction with the "Réseau national de référence anatomo-pathologique des mésothéliomes de la plèvre et des tumeurs rares du péritoine" (Mesopath).

General practitioners, were not directly targeted for the pilot phase. Although not first in line to report new cases of mesothelioma, their contribution is essential in order to ensure that all cases are documented, especially those benefiting from palliative care and not warranting anatomo-pathological diagnosis or hospital treatment. General practitioners (approximately 50,000) have a federal structure, namely the "Collège de la médecine générale" (CMG), which is the representative for the profession at political, professional and institutional levels. The CMG was informed of the launch of the pilot phase and will be updated as the implementation.

In the six regions, the "Agences régionales de santé" (ARS), the regulatory representative of MN and the "Cellules interrégionales d'épidémiologie" (Cire-InVS) have also received specific information and participated actively in the project.

98 cases of mesothelioma were notified during the pilot phase

The results of the pilot phase are overall satisfactory. Ninety-eight cases were notified between 1 January and 30 June 2011 (approximately 120 cases were expected). More than half of them (53%) were reported by a pathologist and 40% by a clinician (chest physician, surgeon, general practitioner, etc.). Seven percent of cases were reported by both a pathologist and a clinician. The length of time taken for a doctor to report a case to the ARS averaged 25 days post-diagnosis and 4 days less (i.e. 21 days) in regions covered by the PNSM. Men were mostly affected, representing 75% of cases on average. Mean age was 70.6 years for both genders. Mesothelioma was located in the pleura and peritoneum in 85% and 11% of cases, respectively. One case of pericardial mesothelioma was reported. The site was not specified for three cases. The question "Any known occupational exposure to asbestos" was answered on 80% of the forms (yes: 45%, no: 26%, don't know: 7%). No information was given for 20% of cases.

A regional variability

The pilot phase highlighted variable situations in the six regions. The situation improved during the pilot phase, except Ile-de-France. The number of notifications progressively increased, probably due to a lack of awareness or an initial poor understanding of the procedure or even reporting errors. The pilot phase did not work well in Ile-de-France despite specific efforts to raise the awareness of key physicians and the active involvement of an occupational disease specialist. Specific actions will also therefore be carried out when implementing the MN.

The InVS also carried out a survey targeting all of the regional agents involved in the pilot regions (ARS, RRC, PNSM, Cire) in order to have their opinion on how this phase was conducted and to highlight any suggestions to improve the national implementation of the system. In addition, mesothelioma specialists, PNSM experts and members of the "Copil" (steering committee) were consulted on a regular basis. Recommendations for implementation were validated by Copil members and the HCSP.

3. Ten key factors for the successful implementation of the system nationwide

The pilot phase has demonstrated a theoretical ability to respond to the two objectives for the MN of mesothelioma. It has identified ten key factors to ensure success at national level.

1 - The need for simple, harmonised communication focusing on stimulating objectives in addition to those of the PNSM and complying with HCSP recommendations.

2 - The need for support from national institutions ["Direction générale de la santé" - DGS, the French National Cancer Institute (Inca - Institut national du cancer), "Direction générale du travail" - DGT, etc.], professional bodies and the Cnom particularly for communication.

3 - Guidance and national leadership by the InVS with good interaction at regional level and with the networks of reporting physicians.

4 - The relevance of supporting regional agents (ARS, Cire, RRC, PNSM) within regional project teams led by the InVS.

5 - The need to clarify the role of each of the regional agents by confirming in particular the institutional role of ARS and their assignments, with support from the Ministry of Health.

6 - The relevance of reporting by both pathologists and clinicians, to cover the full spectrum of the disease and to have complete information on cases of mesothelioma.

7 - The importance of clear-cut, simple reporting procedures: two separate pathologist and clinician forms; with the ARS fax number for the notification [2].

8 - The relevance of involving the RRC to relay information to the reporting physicians and with the support of the Inca, to include mesothelioma MN in good practices.

9 - Adaptation of the general framework to take specific regional features into account.

10 - The importance of communication and regular feedback to health care professionals and regional agents.

4. Next stage: Mesotheliomas are becoming a mandatory disease

The national implementation (metropolitan and overseas regions) of MN for mesotheliomas is introduced since as the Ministry for Health alters Article D 3113-7 of the Public Health Code has stipulated the list of MNDs, further to the approval of the HCSP on 2 November 2011. This MN has targets epidemiological awareness. It imposes stringent constraints, namely to achieve exhaustiveness and to relate this system to the additional collection of information on environmental exposure by surveys. The management of this system is based on national guidance and active regional participation. It should be also supported by professional and institutional bodies, especially the Ministry for Health. This MN should, therefore, reinforce monitoring of mesotheliomas by ensuring the epidemiological follow-up of extra-occupational cases in areas not covered by the PNSM (~70% of the population) and non pleural mesotheliomas (12 to 15%) across the country. It should raise the awareness of one in three cases of mesothelioma developing in targeted populations (non pleural, women, under 50 year-olds) without known occupational exposure to asbestos. The system must also be backed up by surveys, following a procedure common to all the regions. The relevant framework involving dedicated resources has yet to be defined.

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For further informations:

[1] Mandatory notification of Mesotheliomas. Results of the pilot phase and recommendations for a national implementation. Saint Maurice: Institut de veille sanitaire, 2012. 85 p. Available (in French) at the following URL: http://www.invs.sante.fr

[2] Thematic Dossier MN mesothelioma with download forms available at: http://www.invs.sante.fr

Key words: methelioma, mandatory reporting, epidemiological surveillance, France

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